

# How data systems leave older people behind

Southampton



HelpAge International is a global network of organisations promoting the right of all older people to lead dignified, healthy and secure lives.

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# Introduction

This report examines the opportunities and challenges involved in gathering, analysing and making available to decision-makers, practitioners, and older people themselves, the high quality data needed to ensure the inclusion of older populations in global development plans and policies. It addresses both the potential and the limitations of the data that is currently available and describes the range of indicators needed to inform future policy action for the wellbeing of older people.

Researchers know that older people face significant challenges. These range from chronic illness to securing employment and income, to personal safety. But because of gaps in the data, policy makers in many countries do not know the extent of these challenges. There are gaps in knowledge of older people's experience of giving or receiving care, work patterns in later life, and causes of income insecurity. There is a general awareness of the risks to personal safety due to violence or even neglect, but insufficient data to allow for effective policy making and service provision. The absence of data on sexually transmitted disease among older populations in some regions suggests a lack of understanding of the nature of these diseases in terms of their persistence or emergence in later life. These are just some of the issues addressed in this discussion of the state of the data on ageing.

A key problem is the use of age caps in data-gathering. While much research and policy on ageing chronologically defines older age as 60 years and over, this report finds examples where data gathering is capped at the age of 49, leaving those aged just 50 and over unaccounted for in survey data. We also discuss the problem with those surveys which do investigate the lives and experiences of older people but which do not present disaggregated results. To consider an age group spanning 35 years or more as a uniform whole means that lessons about the varied experience of ageing as one advances through later life cannot be learned – or indeed planned for properly, in a policy sense. We strongly recommend that research and statistical data on ageing be disaggregated into smaller five year cohorts so that this variation in health and social experience is clear to those who are developing policies and planning services.

The Global AgeWatch Index set out to capture the multi-dimensional nature of the quality of life and wellbeing of older people, and provide a means to measure country performance and promote structural improvements. This policy report focuses on three of the domains identified: income security, health status, and a key aspect of the enabling environment in later life – freedom from violence and abuse.<sup>1</sup>

On income security we aim to assess both people's access to income and the range and nature of income sources available to them in meeting the basic needs of old age. On health, we comment on data requirements to assess health and wellbeing and discuss some of the current issues and deficits that need to be addressed. The third topic in our report, violence and abuse, explores the freedom to enjoy personal safety and security in older age. Older people themselves identified this freedom as one of their four priorities in the enabling environment domain along with social connectedness, civic freedom and access to public transport. In this report, we examine the availability and quality of data on personal safety and levels of vulnerability to violence and abuse in later life.

We begin in the following section by reviewing progress made in setting ageing agendas globally and identifying the data-related obstacles. We then examine each of our three key topics in turn: income security, health and wellbeing, and violence and abuse, asking what data is available, how it could be better utilised, and what still needs to be collected. While making general observations on the problem of missing data around the world, our focus is specifically on Asian countries. The report goes on to analyse ageing-specific surveys in China, India and Bangladesh, and a general survey in Pakistan which covers some of the issues we address here, before concluding with a series of recommendations.

1. HelpAge International, www.helpage.org/ global-agewatch (23 December 2016)

# Global agendas, commitments and policy development

A key opportunity to influence policy and practice relating to data on older people is provided by the 2030 Agenda for Sustainable Development, agreed by UN Member States in September 2015. The Agenda sets out an aspirational programme for 'all ages', committing to 'end poverty and hunger, in all their forms and dimensions, and to ensure that all human beings can fulfil their potential in dignity and equality and in a healthy environment'. The 17 Sustainable Development Goals (SDGs) and 169 targets set by the UN demonstrate the scale and ambition of this new agenda.<sup>2</sup>

Delivering the transformative vision of the SDGs – to 'leave no one behind' in the universal effort to eradicate poverty and secure peaceful, equitable development – requires fresh policies and robust tools that will measure and secure wellbeing for all, including those in older age. Given the rapid expansion of the numbers and proportions of older people worldwide, the need for action is increasingly apparent and indeed, urgent. As the 2015 UN report on population ageing notes, 'The number of older persons – those aged 60 years or over – has increased substantially in recent years in most countries and regions, and that growth is projected to accelerate in the coming decades.'<sup>3</sup>

There are now around 900 million people aged 60 or over worldwide, representing 12.3 per cent of the global population. By 2030, this is projected to increase to 1.4 billion (16.5 per cent); by 2050, it may reach 2.1 billion or 21.5 per cent of the global population. These demographic changes are most rapid in low-income countries, and by 2050, eight out of 10 of the world's older people will live in less developed regions.<sup>4</sup>

This diverse and growing population is experiencing a wide variation in health and socio-economic status, along with a range of needs arising out of the differing local and national contexts in which they live. Policy makers require much more complex data than is currently available in order to plan effectively to meet both the challenges and the opportunities of population ageing. A key aspect of the SDGs is their data-intensive agenda, which acknowledges that 'Quality, accessible, timely and reliable disaggregated data will be needed to help with the measurement of progress and to ensure that no one is left behind. Such data is key to decisionmaking.'

But the fact remains that both the development of data and the policy frameworks to facilitate its analysis have lagged behind the demographic transition in most regions outside the OECD. The Madrid International Plan of Action on Ageing (2002), endorsed by over 150 UN Member States, produced the foundation strategy in the category of ageing and development. However, while the Madrid plan identified three priorities for action ('older persons and development; advancing health and wellbeing into old age; and ensuring that older people benefit from enabling and supportive environments'), it made only passing reference to the need for improved data collection and analysis. The plan declares that 'Research ... provides essential evidence for effective policies' and calls for 'national data collection and analysis ... for policy planning, monitoring and evaluation', but it makes no further recommendations on how to make this happen in reality.<sup>5</sup>

Despite the obstacles that remain, the international imperative to measure progress in implementing the SDGs agreed by UN Member States has the potential to be a game-changer with regard to data on ageing. The global monitoring framework for the SDGs has begun to highlight weaknesses in international and national data infrastructures, notably in low- and middle-income countries, regarding the collection, analysis, reporting and utilisation of data on older people. The need to redress these weaknesses is urgent.

2. United Nations Department for Economic and Social Development (UNDESA), Division for Sustainable Development, *Transforming our world: the 2030 agenda for sustainable development*, https://sustainabledevelopment. un.org/post2015/transformingourworld (16 November 2016)

**3.** UNDESA Population Division, *World* population ageing 2015 New York, United Nations, 2015, p.1

4. Calculation based on UNDESA Population Division, World population prospects: the 2015 revision, DVD Edition, 2015

5. Political declaration and Madrid International Plan of Action on Ageing www.un.org/en/events/pastevents/pdfs/ Madrid\_plan.pdf paragraph 119 www.helpage.org/global-agewatch (23 December 2016) The economic and social transformations implicit in global population ageing should have, by now, prompted a focus on the collection and analysis of data so that these changes could have been monitored from the outset and effective, evidence-based policies formulated. Instead, we are faced with a persistent lack of data and the absence of an information infrastructure that could be used to inform our understanding of key life experiences in later years. The inadequacy of data makes it impossible to formulate effective, evidence-based policies that would address the changing situation of older persons over time. Gaps in data, then, are not an abstract, non-urgent matter: they may lead to failure to address important policy issues and needs among older age groups. It is equally clear that we are not fully measuring or understanding the social and financial contributions older people make - to name just two dimensions of later life that are often underestimated amidst continuing assumptions of decline and retreat as people age. The first step in addressing these challenging gaps in information and understanding is to achieve a consensus within the research and policy community regarding the data that is missing.

# Data availability

Despite the lack of an overall strategy, data collection and analysis has made some progress, thanks to information gathered in representative surveys of the older age population. These surveys tend to cover a wide range of life experiences, but most address particularly important topics such as health. However, there has been no systematic analysis of the resulting datasets or their comparability both nationally and regionally, and no assessment has been made of the data gaps that remain. As well as these ageing-specific surveys, other sources not limited to the older population can provide useful information. National censuses cover all age groups, and there are also surveys of representative samples that either cover all ages or at least provide some limited information on household members of all ages. The Demographic and Health Surveys (DHS) are one of the most important examples of this type of survey. Furthermore, both the census and DHS questionnaires and microdata are relatively easily accessible.

6. Labour force and Income and Expenditure surveys also provide some data on older people at national levels.

The table below gives an indication of data availability for four countries in Asia.

Country	DHS	Census	Ageing surveys
Bangladesh	2004, 2007, 2011, 2014	2001, 2011	Survey on Population Ageing in Bangladesh, 2014
China	None	2000, 2010	China Health and Retirement Longitudinal Study, 2008, 2011, 2013 Chinese Longitudinal Healthy Longevity Survey 2000, 2002, 2005, 2008-9, 2011-12 Longitudinal Study of the Elderly in Anhui Province, 2001, 2003, 2006, 2009, 2012 Study on global AGEing and adult health (SAGE), 2007-8, 2014
India	2005-6, 2014-15	2001, 2011	Study on global AGEing and adult health (SAGE), 2007-8, 2014 Longitudinal ageing study in India (LASI), 2010
Pakistan	2006-7, 2012-13	None (possibly forthcoming 2017)	None

#### Figure 1: Ageing-related surveys in four countries, 2000-16<sup>6</sup>

Adapted from Teerawichitchainan B and Knodel J, *Data mapping on ageing in Asia and the Pacific: analytical report,* Chiang Mai, HelpAge International, United Nations Population Fund (UNFPA), 2015, www.helpage.org/download/55c227b4c55d3 (23 December 2016)



# Data on income security: key requirements

Any attempt to measure income security in old age must assess the multiple and interacting nature of income sources. Older people, as with people of any age, tend to receive income from at least one of four main sources: work, private transfers (typically from family members), public transfers (for example, pensions) and income from savings and assets. The economic challenge of old age arises from the tendency to find it harder to work as one ages, either physically (at least in some cases, amid wide variation) or in terms of age discrimination in employment, or both. In any case, this implies that older people will need to look to at least one other source from the above list in order to ensure a basic level of income security. Nevertheless, reduced opportunities or capacity to work do not necessarily imply a total retirement from the labour force, particularly in low- and middle-income countries, where many older people work to advanced ages, albeit at lower levels of intensity.

Whether this income is truly secure means assessing not only its adequacy, but also whether it is regular and predictable. There is no simple definition of what is adequate, although there are benchmarks – such as national and international poverty lines – which can be useful points of comparison. Comparing adequacy standards between different countries and contexts also needs to take account of the cost of services, particularly health, which can vary substantially. For example, the level of income required by older people in a country requiring large out-of-pocket healthcare payments will be higher than one where health services and medicines are provided free of charge.

Despite the complex nature of income security in old age, analysis of this issue is commonly limited to measures of "old age poverty" using available survey data. This approach involves using data from income and expenditure surveys to assess the share of older people who live below a given poverty line. The most common methodology used in low- and middle-income countries takes the total income or expenditure of a household where an older person lives, divides it by the number of household members, and compares this per capita expenditure to a given poverty threshold.

Using old age poverty as a measure of income security has a number of limitations. The most obvious is that the method used above does not assess the individual situation of an older person, but that of his or her household. Rather than assessing the specific sources of income received by an older person, it aggregates the entire household's income and infers the situation of an older person from that. This approach assumes that resources are shared equally amongst household members, that household members of all ages have the same consumption needs, and that no economies of scale exist for larger households.

Yet these assumptions may be false. Households may, for example, prioritise children's needs over those of older members. People of different ages have

different needs: children may have higher education costs, older people higher health costs, and family members doing manual labour higher food costs. It is also possible that in many cases, larger households would have economies of scale. The limitations of household data are particularly challenging in low- and middleincome countries, where the majority of older people live with people of younger generations. In this context, it is hard to know if poverty analysis of older age groups is detecting their specific situation, as distinct from that of the wider household.

Analysis of data in Bangladesh and Pakistan shows that measurement of old age poverty is highly sensitive to changes in these assumptions. The figure below shows the relative poverty rate of older people (60 plus) compared to the population as a whole in the two countries, first using the standard poverty measurement (per capita) and then using two common alternative assumptions which take account of economies of scale and different levels of consumption amongst children. For each scenario, the chart shows the percentage point difference between the poverty rate of older people and that of the population as a whole.<sup>7</sup> Strikingly, while older people appear to be less poor than the population as a whole using the standard approach in Bangladesh, and the same in Pakistan, alternative assumptions suggest they are actually poorer. This sensitivity to changes in assumptions has been found in other countries, including Bangladesh and Indonesia.<sup>8</sup> Given that there is little consensus on which assumptions are correct, it is doubtful whether this kind of analysis really provides a meaningful picture of the income security of older people.

### *Figure 2:* Relative poverty rates of older people are highly sensitive to changes in assumptions

(Percentage point difference between poverty rate of older people (60+) and the total population, Bangladesh and Pakistan)



With these limitations in mind, it is clear that there is a need for a more multidimensional picture of old age income security. It is naive to believe that the complex interaction of various sources of income in old age can be captured by one aggregate indicator. A more comprehensive approach would be to build a broader picture of the key sources of income in old age, assess their adequacy in reflecting lived experience, and investigate how these sources of income interact with and complement each other. To assess how easy this would be, we need to review current data and locate key gaps.

Significant data on work in old age is regularly collected by governments, and provides fresh insights when disaggregated and analysed in greater depth. Household data-gathering exercises such as labour force surveys and income and expenditure surveys almost always include questions about the labour activity of different household members. Publications of these surveys commonly include disaggregation of employment and labour force status by age, although they usually use a simple cut-off of 60-plus to present the situation of older people.



Source: Calculation based on Bangladesh Household Income and Expenditure Survey 2010, Pakistan Social and Living Standards Measurement Survey 2013

7. The analysis used a relative poverty line of 50 per cent of median income.

8. See, for example, Khondker BH, Vilela A, and Knox-Vydmanov C, *Old Age Social Protection Options for Bangladesh*, Dhaka, HelpAge International and Bureau of Economic Research, Dhaka University, 2013; also Priebe J and Howell F, *Old-Age Poverty in Indonesia: Empirical Evidence and Policy Options – A Role for Social Pensions*, Jakarta, TNP2K Working Paper 07-2014, 2013 The figures below show different levels of disaggregation of this data and highlight important findings. They demonstrate clearly that a significant share of older people, between 30 per cent and 59 per cent of men, and between 5 per cent and 21 per cent of women, continue to work beyond the age of 60. Nevertheless, there remains a strong correlation between advancing age and decreasing labour force participation rates, with people in their 70s and 80s much less likely to be employed than those in their 60s.

### *Figure 3:* Many older people continue to work past the age of 60 ...

**Figure 4: ... yet levels of economic activity decline with age** (Share of population 60+ in







The same surveys also include questions on the number of hours worked, the nature of work, for example sector, and the reasons why some individuals do not work, all of which can provide a deeper understanding of the situation of older people. For example, the chart below shows that people who do continue to work beyond their 50s are less likely to work long hours than their younger peers.

# *Figure 5:* Employed older people are less likely to work long hours than their younger peers

(Share of people in employment working less than 40 hours per week)



Source for Figure 5: calculation based on Bangladesh Household Income and Expenditure Survey 2010, WHO SAGE China 2007, WHO SAGE India 2007

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Source for Figures 3 and 4: calculation based on Bangladesh Household Income and Expenditure Survey 2010, Pakistan Social and Living Standards Measurement Survey 2013, WHO SAGE China 2007, WHO SAGE India 2007 This data also has limitations, and there is scope for improving the clarity and relevance of the survey questions. A major limitation of the data on work and income from these surveys is that it rarely gives a complete picture of the amount of income earned by individuals of different ages. For some professions, data on income levels may be collected, but not for categories such as the self-employed and those working in family businesses. This is the case for people of all ages, and there is no simple methodological solution to this problem.

Data on the extent of family support is limited in surveys regularly carried out at a country level. Regular household surveys provide little insight into the levels of transfers received by older people from their families and others. Neither of these surveys provides any information on how resources are shared within households. Although some include analysis on the level of transfers from other households, including remittances, the specific individual and recipient are not pinpointed.

In contrast, surveys of older people are being used in a number of countries to assess the nature of income support provided by families. In Asia, countries including China, Myanmar, the Philippines and Thailand have surveys of older people that include questions about levels of income received from their children and – in some cases – those transferred to them. These questions are also usually designed in such a way that it is possible to compare the relative importance of income from family with other sources (pensions, work, etc). Unfortunately, the two ageing-focused surveys used here – the World Health Organization (WHO) Study on global AGEing and adult health (SAGE) surveys in China and India – do not include data on transfers of income from families to older people and vice versa.

Survey data on social protection has great potential to shed new light on its role and effectiveness. This is particularly relevant as more and more countries are expanding their pension systems. The most notable example in the four countries studied here is China, which has dramatically expanded pension coverage in recent years, particularly to rural residents: since 2009, more than 130 million older people have started receiving a pension. One benefit of household income and expenditure surveys is that they create the possibility of triangulating receipt of social protection payments with other indicators. For example, are programmes for the poorest well targeted? Are recipients mostly in urban and rural areas? What is the impact on poverty of existing social protection schemes?

The weaknesses in survey questionnaires constitute lost opportunities. One problem is that classification of programmes can be too general. For example, respondents may be asked whether they receive pensions, but not the specific schemes, contributory and non-contributory, in which they participate. The question is often asked at the household level – does anyone in the household receive a particular transfer? – rather than which specific individual receives it. Thus we may learn that someone in the household receives a given benefit, but not whether the older person is the direct recipient. Similarly, in a household with an older couple, we may not find out whether both older people receive a transfer. These gaps in detail hugely limit the extent to which it is possible to undertake gender analysis of receipt of social protection transfers. Paradoxically, the two household surveys included in this study were found to be stronger in some respects than the SAGE surveys, which provide limited data on receipt of social protection.

# Data on health and wellbeing

While our understanding of health as we age has become increasingly nuanced and sophisticated, with a greater appreciation of the broader determinants of health among researchers, health professionals and ageing experts, mainstream policy and datasets have yet to catch up with this change in thinking. A more holistic response to health and wellbeing in older age requires data which not only investigates the specific health issues faced both by older individuals and populations but also assesses the complex interactions of ageing adults with their wider families, households and communities. Housing types, the accessibility of the physical environment, levels of adaptation to need, social participation, income adequacy and social protection are just some of the factors that may be involved.

We are seeking to understand both the individual impact of each of these factors and their combined contribution. As older populations grow in number, they also become more diverse. For example, while average life expectancy at birth is rising in almost all countries, there is evidence that the health of the poorest quintile is not improving at the same rate as that of the richest quintile. There is thus a pressing need for data to be collected across the life course and then disaggregated by age but also by social group, gender, disability, ethnicity and location, to draw attention to the differentials in health and life expectancy within ageing populations.



### **Trends in data collection**

While a number of data sets address health and ageing, they share key shortcomings related to the categorisation of age in the collection and dissemination of data. Examination of a number of frameworks illustrates how older age groups are passively neglected or actively excluded from indicators, resulting in further entrenchment of age-related data gaps. For example, WHO's Non-Communicable Disease (NCD) Global Monitoring Framework uses an age-bracketed indicator on unconditional probability of dying from four main NCDs, limited to the ages of 30-70. Yet we know that people are more likely to have NCDs as they age, a trend which obviously continues, and often accelerates past the age of 70.<sup>9</sup> In a further example from the same framework, a national systems response indicator on cervical cancer screening is age-limited, tracking the 'proportion of women between the ages of 30-49 screened for cervical cancer at least once, or more often, and for lower or higher age groups according to

9. www.who.int/nmh/global\_monitoring\_ framework/en/ (13 February 2017) national programmes or policies'. Screening tends to be offered to women up to a certain age, yet cervical cancer continues to occur in older women. A recent study in the US by Johns Hopkins University School of Public Health found cervical cancer death rates are much higher in older women than previously thought, with many of those dying over the age of 65.<sup>10</sup>

Another gap can be identified in the WHO STEPwise approach to surveillance (hereafter, STEPS), a survey mechanism for collecting national level data on risk factors for NCDs.<sup>11</sup> To date, these surveys have been conducted in 102 countries around the world. The STEPS approach focuses on obtaining core data on the established risk factors for NCDs. Despite the prevalence of chronic disease amongst people in older age, STEPS surveys in at least one major region are rarely conducted with people over the age of 64.<sup>12</sup>

The WHO and World Bank report, Monitoring progress towards universal health coverage at country and global levels: framework, measures and targets (2014), suggests illustrative indicators on access/coverage and on the financial aspects of universal health coverage (UHC). The framework sets out the principle that measures of coverage of health services and financial protection should benefit the entire population throughout the life course, including all ages and both genders, but definitions of indicators are not included.<sup>13</sup> The UNAIDS Global AIDS Response Progress Reporting (GARPR) tool includes age-bracketed indicators on knowledge of prevention (ages 15-24), condom use among people with multiple sexual partnerships, prevalence in antenatal clinics, male circumcision, intimate partner violence and discriminatory attitudes (ages 15-49 in all cases).<sup>14</sup> The incidence indicator (also used in the SDGs) does not include a 50-plus age category, suggesting that it is capped at 49. In population-based HIV impact assessments, inclusion by age is at the discretion of individual countries. These surveys began in 2016, some with no upper age limit, some planning to cap data collection at age 64. Such age cut-offs, alongside those typical of the cervical cancer surveys reported previously, provide an impenetrable barrier to analysing and understanding the potentially serious health impacts of sexually transmitted disease on older age groups.

The focus on UHC in the SDGs creates an opportunity to address a range of obstacles older people face in accessing health and care services. Measuring UHC, including access to safe, effective and affordable essential medicines, requires data on healthcare access, addressing issues such as transportation, physical access to facilities, and staff skills, knowledge and attitudes. There are shortcomings in the data sources typically used to populate these indicators. For example, current SDG indicators to measure UHC include an access indicator relating to tracer interventions. Treatment for hypertension and diabetes is included here. Where the data is drawn from Demographic and Health Surveys (DHS) or STEPS surveys, limited information will be available for older people. DHS surveys normally exclude women aged 50 and over, and men aged 55 or 60 and over; and WHO guidance suggests the inclusion of people only up to age 69 in the case of STEPS.<sup>15</sup>

The context for the SDG health targets is that health and care systems in many countries are ill-prepared to cope with the increasingly complex and overlapping health and social care needs of people as they age. A critical data gap here relates to unpaid care, including that provided by older people themselves who are frequently carers of spouses and other family members, as well as care provided by neighbours and volunteers in the wider community. The SDG targets recognise unpaid care, including through social protection policies, but not the role of older people in its provision. The indicator, measuring time spent on unpaid domestic and care work, is not age-restricted, but detailed meta-data analysis shows limited collection of data on unpaid work and care at national level and inconsistent use of age cohorts.<sup>16</sup>

10. www.jhsph.edu/news/news-releases/ cervical-cancer-death-rates-higher-amongolder-and-black-women.html

11. www.who.int/chp/steps/riskfactor/en/ (13 February 2017)

12. Of around 40 countries in Africa that have conducted a STEPS survey, only six have included people over the age of 64 in their most recent survey (up to 69 in Kenya, Uganda and Swaziland, 74 in Mauritius. There was no upper limit in Zambia and Zimbabwe but only very limited age disaggregation was included in the reports).

13. http://apps.who.int/iris/bitstream/10665/ 112824/1/WHO\_HIS\_HIA\_14.1\_eng.pdf?ua=1 (22 February 2017)

14. https://aidsreportingtool.unaids.org/static/ docs/GARPR\_Guidelines\_2016\_EN.pdf (5 February 2017)

15. www.who.int/chp/steps/resources/ FactSheetAnalysisGuide\_V3.1.pdf?ua=1 (5 February 2017) www.who.int/chp/steps/ resources/sampling/en/ (5 February 2017)

16. http://unstats.un.org/sdgs/files/ metadata-compilation/Metadata-Goal-5.pdf (5 February 2017)

### Data on ageing and health: key requirements

In its recent *World report on ageing and health*, WHO sets out the core issues to be addressed in the context of rapidly ageing populations. The report says that 'Determining whether people are living longer and healthier lives, or whether the added years of older age are lived mainly in poor health, is crucial for policy development.'<sup>17</sup> Answering this question will require greatly enhanced collection, analysis, reporting and utilisation of data regarding the health and wellbeing of older people. However, achieving this objective will be fraught with challenges. First, while the term is widely used, there is as yet little agreement on how to define and measure healthy ageing.<sup>18</sup> Secondly, the data required for an evidence base for effective policymaking in response to this critical issue is lacking, owing to the fragmentary and contradictory nature of research on health in older age. While data from low- and middle-income countries remains inadequate, that from high-income settings, such as OECD countries, is also often inconsistent. These challenges make the identification both of good quality data and the gaps in data a vital part of the task for researchers and policy makers.

A key starting point is to construct a framework for healthy ageing, one which emphasises sustaining active, healthy independent living as far as possible, enabling older people with chronic conditions to live well and maintain a high degree of functioning for as long as possible. Using this framework, we can set out the basic questions to address regarding health and wellbeing in older age, which relate to the core issue raised by WHO above.<sup>19</sup>

For evidence of intrinsic capacity and functional ability, we need to know whether rising longevity is experienced as additional years of good health, measured by functional ability. Are years of healthy life extending, or are more years being lived in poor health?

In measuring functional ability, what are the respective contributions of an individual's intrinsic capacity and what are the environmental factors influencing levels of functioning in later life? How do older individuals interact with their environment as they age? We also need to know the causes of the variations in physical and mental capacity and functional ability between individuals from apparently similar backgrounds, and whether these variations are growing or decreasing over time. Further, what are the measurable indicators of disease(s) and which supportive (health and/or social care) interventions are instrumental in maintaining functioning? Which of the latter should be prioritised to maintain functional capacity, and at what stage of the life course? How can we overcome the lack of data on mental health, with dementia in particular being seriously underdiagnosed globally, and the difficulties in collecting it?

We also need to learn how health systems, especially in low- and middle-income countries, could shift from a curative emphasis to a more integrated approach. It has long been clear that there is an increasingly overlapping need for both health and social care interventions as people age and as they learn to manage the long-term challenges that accompany chronic illness. How would more integrated approaches to health and social care work in practice in different national contexts? To gather the evidence necessary for designing effective social support systems, we must be able to assess, in situations where older people need ongoing social support, as opposed to healthcare, what those support needs are, how and if these needs are currently met, and how future service provision could be improved. This recalls the point made earlier about the role of older people as carers. As crucial as it is to learn about the range and diversity of care needs in later life, we must also be able to track the contribution of older people who themselves are carers. How many are there? What is the value of this unpaid care, and what are healthcare services saving as a result? Do older carers also need support, enabling them to continue looking after family members who are ill or disabled, without becoming ill themselves? How can health and social policy adapt to this apparently growing trend?

17. WHO, World report on ageing and health, Geneva, WHO, 2015, p.49

**18.** WHO, World report on ageing and health, p.25

**19.** WHO, World report on ageing and health, 2015, p.227



Clearly, a key step is to be able to measure health in all its dimensions; we need the data. In order to reverse this serious paucity of information, data on levels and distribution of health and disability among older populations, as well as morbidity trajectories, are needed, enabling the development of validated standardised measures capable of assessing the determinants of intrinsic capacity and functional ability within and between age cohorts. This requires large-scale longitudinal research studies in multiple settings. At present, we are some distance from achieving this, particularly in low- and middle-income countries.<sup>20</sup> Even for high-income countries, the evidence from longitudinal studies is uneven, making it difficult to establish whether specific interventions have an impact on observed determinants of health and wellbeing. For low- and middle-income countries, disaggregated data, in particular by age and sex, is almost entirely absent, and as noted above, the SDG indicators relating to NCDs set specific age boundaries, reflecting adherence to the concept of 'premature mortality' (defined by WHO as dying before the age of 70).<sup>21</sup> For Lloyd-Sherlock (2016), restricting interest in mortality to those aged under 70 'sends a strong signal in favour of discriminating against older people in the allocation of health resources and the collection of data'.22

Data relating to health systems in low- and middle-income countries is no easier to find than that on population health and wellbeing. There is very limited evidence on service provision for older individuals or populations, from health promotion, illness prevention and screening, to management of long-term conditions and social support. Nor is there data from which to develop indicators for integrated health and social care management in both institutions and home settings.

The health-related costs of ageing populations is another key data gap, again related to the inadequacy of information on intrinsic capacity and functional ability. In addition, socio-economic status is critical, as is the configuration of health and care systems, as well as the financing models in place in different jurisdictions. Despite this lack of data, assumptions regarding the effects of population ageing on health spending tend to project sharply rising costs – very possibly erroneously, since the relationship between health needs and expenditure, particularly in low-and middle-income countries, is tenuous.<sup>23</sup>

In a partial response to some of these issues, the most significant data initiative relating to the health of older people in the past two decades has been WHO's Study on global AGEing and adult health (SAGE), examples from which have already been cited in this report. Launched by WHO in 2002, multiple waves of SAGE data collection have resulted in health and wellbeing data on over 34,000 adults aged over 50 from a range of low- and middle-income countries.<sup>24</sup> SAGE provides health, disability, chronic conditions, risk factors and healthcare utilisation data that is comparable to studies in high-income countries, such as the US Health and Retirement Study family of studies.

20. Kowal P et al, 'The World Health Organization Study on global AGEing and adult health (SAGE)', *International Journal* of Epidemiology, 41, 2012, pp.1639-1649

21. 'Premature mortality, measured in terms of potential years of life lost (PYLL) before the age of 70 years, focuses on deaths among younger age groups of the population.' (from Health at a Glance 2011: OECD Indicators, OECD Library)

**22.** Lloyd-Sherlock P et al, Institutional ageism in global health policy, *BMJ* 354: i4514, 2016, DOI: 10.1136/bmj.i4514

23. Lloyd-Sherlock P et al, Population ageing and health, *Lancet*, vol. 379, No. 9823, 2012, pp.1295-1296

**24.** China, Ghana, India, Mexico, the Russian Federation and South Africa

In addition to the core research, SAGE has fostered additional data collection initiatives, such as the SAGE-INDEPTH collaboration. This has already generated one wave of health, disability and wellbeing data in eight health and demographic surveillance system field study sites in four African and four Asian countries. A SAGE-HIV study on the direct and indirect impacts of HIV, anti-retroviral therapy and caregiving on older adults has generated three waves of data in Uganda and South Africa.<sup>25</sup> Successive waves of SAGE surveys have built a more comprehensive approach to identifying factors impacting on health in older age and the ageing process. Standardised survey instruments, methodology, interviewer training and translation protocols are used in all SAGE countries, and the SAGE questions reflect a broad set of measures ranging from subjective perceptions of health and wellbeing, to household, societal and environmental factors. Though still in the early stages of generating the evidence resulting from data collection, SAGE makes substantial progress in providing data to answer questions relating to functional ability and intrinsic capacity in older age in a handful of countries. Nevertheless, challenges remain, due in part to the lack of funding for analysis and publication of findings. This has meant, for example, that in the case of SAGE surveys conducted in China and India in 2014, results are not due before 2017.

# Data on violence and abuse

The right to lead one's life with a sense of personal safety, free from cruel and degrading treatment or the infringement of one's privacy, is enshrined in the Universal Declaration of Human Rights.<sup>26</sup> Violence and abuse against a person, regardless of race, sex, age, disability or other socio-economic characteristics, is a violation of human rights and fundamental freedom.

A number of international initiatives, including the UN Principles for Older People, the Madrid International Plan of Action on Ageing, and the Toronto Declaration on the Global Prevention of Elder Abuse, amongst others, define violence and abuse, call for elimination of all its forms, and recommend the development of structures and support services to respond to and prevent further abuse.<sup>27</sup> Despite these declarations, progress has lagged, in part due to the scarcity of data on violence and abuse in later life. The Human Rights Council's Independent Expert highlighted this lack of reliable information as one of the obstacles to the promotion and protection of human rights in later life and additionally called for a gender perspective in research into the nature and extent of violence and abuse.<sup>28</sup>

Data on violence and abuse in later life is gathered through various channels, including dedicated surveys, ageing surveys, general surveys on health, administrative data generated by health and social services and police, academic research and civil society programmes.

Administrative data is a potentially valuable resource for identifying vulnerable groups who have reported incidents or sought support services in relation to violence and abuse. These statistics are already collected and do not entail significant additional costs for survey budgets. If data is part of an official statistical system it tends to be systematically collected and updated, allowing for comparability and historical analysis. However, a particular limitation of administrative data is that it only captures reported cases of violence and abuse. It is estimated that only one in 24 cases of elder abuse is reported and that due to the systemic barriers to reporting such crimes, such as the lack of dedicated services or trained staff, or the poor quality of documentation, the abuse of some subgroups of the population is clearly not captured in this way.<sup>29, 30</sup>

Additionally, when administrative data is collected, it may not be disaggregated by age and gender. For example, official crime statistics published by the Pakistan Bureau of Statistics do not permit an accurate assessment of the degree and nature of violence and abuse experienced in later life, since there is no disaggregation of data by age, sex, disability and location.<sup>31</sup>

**25.** Kowal P et al, 'WHO Study on global AGEing', *International Journal of Epidemiology*, 41, 2012, pp. 1639-1649

26. UN Universal Declaration of Human Rights, Articles 3, 5, 15, www.un.org/en/ udhrbook/pdf/udhr\_booklet\_en\_web.pdf (23 December 2016)

27. UN Principles for Older People, www.ohchr.org/EN/ProfessionalInterest/ Pages/OlderPersons.aspx (23 December 2016); Madrid International Plan of Action on Ageing, www.un.org/en/events/pastevents/ pdfs/Madrid\_plan.pdf (23 December 2016); The Toronto Declaration of the Global Prevention of Elder Abuse, www.who.int/ ageing/projects/elder\_abuse/alc\_toronto\_ declaration\_en.pdf (23 December 2016)

28. Human Rights Council, Report of the independent expert on the enjoyment of all human rights by older persons, A/HRC/33/44, 2016, http://ap.ohchr.org/documents/alldocs. aspx?doc\_id=26860, p.12-13 (23 December 2016)

29. Administrative Data Liaison Service, Administrative data introduction, www.adls. ac.uk/adls-resources/guidance/introduction/ (23 December 2016)

**30.** WHO, *Elder abuse*, fact sheet, 2016, www.who.int/mediacentre/factsheets/fs357/ en/ (23 December 2016)

**31.** Pakistan Bureau of Statistics site, crime reported by type, www.pbs.gov.pk/sites/ default/files//tables/Crimes%28website%29. pdf (20 November 2016) Surveys are important tools for gathering information on perpetrators and assessing the prevalence of violence and abuse in later life, the impact of violence and abuse on a victim, the barriers that prevent reporting such crimes, the degree of victims' awareness of grievance mechanisms, and the effectiveness of interventions. Surveys reach both victims and those who are unaffected, and provide additional information about victims' socio-economic and health status, household composition and environment, etc. Furthermore, dedicated surveys may offer more breadth and scope, covering various aspects of violence and abuse, and should be administered by appropriately trained staff who are able to conduct the process sensitively and ethically. This would help to address some of the under-reporting challenges currently faced and build a more complete and nuanced picture of abuse.

Currently there is no single dedicated survey or range of harmonised surveys that measure forms of violence and abuse against older men and women and that have an extensive country coverage like the DHS or Multiple Indicator Cluster Surveys (MICS). Existing surveys have been limited in scope: they have either focused on gender-based violence (such as the International Violence Against Women Survey), analysed a few countries or one region (for example, the Prevalence Study of Abuse and Violence against Older Women in Austria, Belgium, Finland, Lithuania and Portugal), or restricted the target population to respondents aged 15-49.<sup>32</sup> Older people are excluded from surveys such as WHO's Multi-country Study on Women's Health and Domestic Violence against Women, and the DHS.

National surveys on elder abuse are still rare. A review in 2014 of national population-based surveys on elder abuse in 133 countries shows that only 17 per cent of countries reported having conducted a national survey on elder abuse. Some 34 per cent of high-income countries and 5 per cent of low-income countries had conducted such a survey. In low-income countries that do gather information on types or categories of violence (sexual violence, intimate partner violence, youth violence, etc), abuse of older adults is the least surveyed category.<sup>33</sup>

A lack of regular, comprehensive data on violence and abuse against older people makes it difficult to develop evidence-based policies and monitor progress on this issue.



### *Figure 6:* A review of national surveys on elder abuse and laws against it in 133 countries shows that:

Source: WHO et al, *Global Status Report on Violence Prevention* 2014, Full report, Table 3, joint publishers WHO, UN Development Programme and UN Office on Drugs and Crime, 2014, p.23

Both ageing-specific and general surveys that collect confidential information on respondents' health are valuable tools for gathering sensitive data on prevalence of violence and abuse. However, due to a lack of internationally agreed guidelines on the inclusion of questions on this difficult topic – one still marked by stigma in many cultures – the amount of information gathered varies by survey. The mapping of data on ageing in 25 Asia-Pacific low- and middleincome countries shows 10 countries conducting age-specific surveys, but only four collecting data on experience of elder abuse.<sup>34</sup>

32. Luoma M L et al, Prevalence Study of Abuse and Violence against Older Women. Results of a Multi-cultural Survey in Austria, Belgium, Finland, Lithuania, and Portugal (European Report of the AVOW Project). Finland: National Institute for Health and Welfare (THL), 2011

**33.** WHO et al, *Global Status Report on Violence Prevention* 2014, Full report, Table 3, joint publishers WHO, UN Development Programme and UN Office on Drugs and Crime, 2014, p.23

34. Teerawichitchainan B and Knodel J, Data mapping on ageing in Asia and the Pacific: analytical report, Chiang Mai, HelpAge International, United Nations Population Fund (UNFPA), 2015, www.helpage.org/download/ 55c227b4c55d3 (23 December 2016) These limitations are also reflected in existing reviews and guidelines. For example, to support countries to measure gender-based violence, the United Nations Department of Economic and Social Affairs Statistics Division (UNDESA) published guidelines on survey design, data collection, analysis, and reporting statistics on violence against women, and took stock of current knowledge on neglect, abuse of and violence against older women.<sup>35, 36</sup> However, there are no such guidelines for violence and abuse in later life among both men and women. A number of initiatives aim to address some of these gaps. For example, a recent multi-country study developed a survey tool, based on the Office of the High Commissioner for Human Rights good practice model, to measure violence and abuse against older men and women, and collected data in three countries.<sup>37</sup>

To understand violence and abuse in later life we need to measure different types of abuse, for example physical, sexual, emotional, financial, or neglect perpetrated by either an intimate partner, carer, or strangers in the case of violence and abuse. We need to be able to identify those older people who are more likely to be victims of violence and abuse: risk factors include disability, poor physical health, mental health, poverty, social isolation, and housing arrangements in which an older person lives with a perpetrator.<sup>38</sup> The survey should collect personal characteristics to help identify sub-groups of those most vulnerable to violence and abuse. It is important to distinguish between abuse caused by an intimate partner, another person of trust, or strangers. Surveys also need to attempt to measure frequency and duration of abuse, as well as to identify channels through which victims seek help.

Analysis of age-specific and general surveys from Bangladesh, China, India and Pakistan illustrates some of the limitations in data gathering on violence and abuse in later life, and identifies opportunities to improve current data tools.<sup>39</sup>

# Ageing-specific surveys in China, India and Bangladesh

China, India and Bangladesh have all conducted ageing surveys since 2010. Together, China and India have each carried out two waves of WHO SAGE as well as national longitudinal studies, the Chinese Longitudinal Healthy Longevity Survey (CLHLS), China Health and Retirement Longitudinal Study (CHARLS), and the Longitudinal Ageing Study in India (LASI). The Bangladesh survey was carried out in 2014. Pakistan has not yet conducted an ageing-specific survey.

Ageing surveys tend to cover a similar range of topics: socio-demographic characteristics of household members, financial and in-kind transfers to and from a household, respondent's health status and functionality, access to and utilisation of healthcare services, past and current employment status, pensions, household income and expenditure, and housing characteristics. The inclusion of questions on violence and abuse and the amount of information requested varies by survey.

### China

Rapid economic growth and changing socio-economic trends such as urbanisation and changes in traditional values have exposed the vulnerable situation of certain subgroups of older people who are either alone, have limited family support or live in financial insecurity.<sup>40</sup> A study of violence and abuse against older rural men and women in one Chinese province found that 36 per cent of respondents age 60 and older experienced at least one type of violence and abuse in the past year. Nearly 11 per cent of older people experienced at least two types of mistreatment. The most common abuse is emotional, reported by 27 per cent of respondents, followed by caregiver neglect (16 per cent of respondents). Older people who are depressed, single (either widowed, divorced or separated), have a physical disability, hold a labour-intensive job, receive income only from employment, or live alone are at higher risk of experiencing violence and abuse.<sup>41</sup>

China has at least three longitudinal studies on ageing (WHO SAGE, CLHLS and CHARLS) which regularly collect data on the health and wellbeing of older people. WHO SAGE has collected data on adults age 50 and older in 2002-04, 2007-10 and 2014, with another round tentatively scheduled for 2017.<sup>42</sup> The CHARLS study has gathered information on people aged 45 and older every two years since 2011.<sup>43</sup>

**35.** UNDESA Statistics Division, Guidelines for Producing Statistics on Violence against Women – Statistical Surveys, New York, United Nations, 2014

**36.** UNDESA Division for Social Policy and Development, *Neglect, abuse and violence against older women*, New York, United Nations, 2013, www.un.org/esa/socdev/ documents/ageing/neglect-abuse-violenceolder-women.pdf (23 December 2016)

**37.** Vizard P, Developing an indicator-based framework for monitoring older people's human rights: panel, survey and key findings for Peru, Mozambique and Kyrgyzstan (Centre for Analysis of Social Exclusion and HelpAge International, 2013)

**38.** WHO, World report on ageing and health, 2015

**39.** The reviewed surveys include: WHO Study on global AGEing and adult health (SAGE) in China and India, China Health and Retirement Longitudinal Study (CHARLS), the Longitudinal Ageing Study in India, Pakistan Demographic and Health Survey (DHS), and Pakistan Social and Living Standards Measurement Survey (PSLM).

**40.** Wu L et al, 'Prevalence and Associated Factors of Elder Mistreatment in a Rural Community in People's Republic of China: A Cross-Sectional Study', *PLoS ONE* 7(3): e33857 2012 doi:10.1371/journal.pone. 0033857 (23 December 2016)

**41.** Wu L et al, 'Prevalence and Associated Factors of Elder Mistreatment' (2012)

42. Study on global AGEing and adult health, Wikipedia, https://en.wikipedia.org/wiki/ Study\_on\_Global\_Ageing\_and\_Adult\_Health (6 December 2016)

43. China Health and Retirement Longitudinal Study, Peking University, http://charls.pku. edu.cn/en/page/about/CHARLS (6 December 2016) The CLHLS study collected data on the population aged 65 and older between 1998-2012.<sup>44</sup> Longitudinal surveys are potentially a useful tool for understanding and tracking the prevalence of violence and abuse in all forms and in different contexts, along with risk factors, relationship between victim and perpetrator, and the long-term impact on victims.<sup>45</sup> However, two of the surveys mentioned here, CHARLS and CLHLS, do not include any questions on violence and abuse, and the third survey includes questions on just one type of violence or physical abuse.

CHARLS does collect detailed information about various population subgroups in later life, allowing a nuanced view of the range of physical and cognitive capacities among older people, as well as states of mental health, and particularly depression, and levels of functionality. However, it excludes issues of violence and abuse.

SAGE does not have a stand-alone module on elder abuse or violence and abuse. It includes a few questions as part of two different modules, one on social cohesion and one on chronic conditions and health service coverage. The questions are more general in nature, gauging whether an older person feels safe at home alone, walking alone in the street after dark, and whether the respondent or anyone else in the household was a victim of a crime over the last 12 months. Questions in the chronic conditions module focus on bodily injuries, specifically whether they were self-inflicted or caused by someone else, whether an injury resulted in disability, and whether medical treatment was sought.

While SAGE collects data on physical injuries intentionally inflicted on individuals aged 50 and over, and allows examination of prevalence by various subgroups of older people (sex, age and location), and by risk factors (poor physical health, cognitive ability, and socio-economic level of household), it is not possible to accurately gauge overall prevalence of physical violence in later life. The survey does not define types of physical violence and abuse, such as hitting, beating, kicking, pushing, slapping, choking, throwing objects at someone, threatening with a weapon, etc. WHO SAGE also does not measure neglect or sexual, emotional or financial abuse. Additionally, it does not collect information on frequency and history of injuries, whether they were caused by an intimate partner or not, and whether the incident was reported to someone other than a medical professional. This highlights a challenge that broad-themed surveys may face, since they have to strike a balance between more in-depth information on the one hand and the problems of expanding length and cost of the survey on the other.



44. Chinese Longitudinal Healthy Longevity Survey, Institute for Social Research, University of Michigan, www.icpsr.umich. edu/icpsrweb/NACDA/studies/36179 (28 December 2016)

**45.** Xin Qi Dong, 'Elder Abuse: Systematic Review and Implications for Practice', *Journal of the American Geriatrics Society* 63:6, June 2015, pp.1214–1238 doi: 10.1111/jgs.13454 (23 December 2016)

#### India

A survey conducted by HelpAge India in 2014 in 12 cities across the country reported that 53 per cent of older women and 48 per cent of older men had experienced violence and abuse.<sup>46</sup> Some 46 per cent of older people reported that they had experienced abuse in the past three to five years, and 25 per cent in the last one to two years. Fully 35 per cent of older people reported that they were abused at least once a week, 20 per cent once a month, and 17 per cent almost daily. Verbal abuse was the most prevalent type of mistreatment, reported by 41 per cent of respondents, followed by disrespect (33 per cent) and neglect (29 per cent). Within a domestic setting, daughters-in-law and sons were identified as most common perpetrators of violence and abuse (61 and 59 per cent respectively). Yet 41 per cent of older people did not report incidents. Asked why they did not do so, 59 per cent said they wished to keep it private, while 17 per cent said they did not know how to deal with this problem. Those who did report it primarily sought help from a relative, friend or other family member. Only 18 per cent reported it to social services and 12 per cent to police.

The Longitudinal Ageing Study in India collects information on the economic, physical and social wellbeing of people age 45 and older. It is expected to be administered biennially over 25 years.<sup>47</sup> The survey does not include a module on violence and abuse, and the general nature of many of the questions allows for only a very limited view of injuries and disability caused by others; they are not specific enough to measure physical, sexual, emotional, financial abuse or neglect in later life. The housing questionnaire includes a question on perceived level of safety in the neighbourhood where the respondent lives. The module on health asks about injuries experienced in the past two years. Follow-up questions clarify the cause of the injury (traffic accident, interpersonal violence, animal attack, other) and whether medical treatment was sought. The employment module includes questions on disability, asking when a respondent became disabled, how this came about and whether it was work-related or not. The survey does not assess whether injuries and disability were caused by an intimate partner or someone else, the history and frequency of injuries experienced, and whether the respondent reported the incident to anyone other than health services. SAGE for India has the same limitations of SAGE China discussed above. Thus two regularly administered surveys on ageing in India do not collect core information on violence and abuse in later life.



**46.** HelpAge India, *State of elderly in India* 2014, New Delhi, HelpAge India 2015, www.helpageindia.org/images/pdf/ state-elderly-india-2014.pdf (23 December 2016)

**47.** Longitudinal Ageing Study in India, http://iipsindia.org/pdf/LASI\_brochure.pdf (23 December 2016)

### **Bangladesh**

A study of elder abuse in one district of Bangladesh identified poverty as a risk factor for violence and abuse, with 62 per cent of older people in poor households experiencing abuse, compared to 6 per cent of older people from wealthy households.<sup>48</sup> Neglect is the most prevalent form of abuse; 60 per cent of older respondents living in poverty reported neglect, with 7 per cent reporting abandonment and 6 per cent reporting emotional abuse. Another study of violence and abuse of older people in the informal settlements of Dhaka City shows that older women are disproportionately affected; 54 per cent of those who had been neglected were older women, and 53 per cent of older women had experienced emotional abuse compared with 47 per of older men.<sup>49</sup>

In 2014, a survey on population ageing in Bangladesh was developed, but to date no official information about the survey has been made available in English and no questionnaire template, final report or micro data have been released. This lack of transparency is coupled with the limited amount of data gathered on violence and abuse in later life. The Bangladesh National Action Plan to Prevent Violence Against Women and Children (2013-2025) lists four sources of data on violence against women: one is a review of data by the Bangladesh Institute of Development Studies and three are surveys of violence against women and children. Of these, one was conducted by the Multi-sectoral Programme on Violence against Women (2008), one by the International Centre for Diarrhoeal Research Bangladesh (2006), and the third by the Bangladesh Bureau of Statistics (2011). The target population group in the first two of these surveys were those aged 15-49; only the latter survey interviewed women aged 15 and older, and reported both current and lifetime prevalence of physical and emotional violence, as well as financial abuse perpetrated either by an intimate partner or non-partner. The data gathered in this survey was disaggregated by age (eg 50-54, 55-59, and 60-plus), and by urban and rural residence.<sup>50</sup>

### **General surveys**

The Demographic and Health Survey is an example of a general survey which is not age-specific, covering population demographics, health, HIV, and nutrition. The DHS Programme collects and publishes representative data in over 90 lowand middle-income countries.<sup>51</sup> A standardised survey is typically administered about every five years. All ever-married women aged 15-49 and men aged 15-54 or 59 and over residing in a household are eligible for an interview. The DHS includes a stand-alone module on domestic violence and abuse that, at the discretion of individual countries, can be included as part of the standard DHS survey. To date, 59 countries, including Bangladesh, India and Pakistan, have collected data on violence and abuse. However, only one female aged 15-49 is interviewed per household.

The module includes 32 questions that cover all core dimensions of violence and abuse. It captures three types of violence: emotional, physical and sexual. The module establishes a timeframe by asking about the history of abuse against both ever-married or partnered women and those who have never been married, partnered nor lived with a man since the age of 15. It also measures frequency of violence during the last 12 months. The module identifies a relationship between a female respondent and a perpetrator by considering violence caused by intimate partner, family member, friend, teacher, employer, police, religious leader, stranger or other individual. The DHS survey enables the examination of the prevalence of violence against diverse subgroups of women and makes it possible to identify risk factors. It collects personal information about respondents: age, level of education, marital status, residence and employment status. The age and educational attainment of intimate partners and other members of household is also collected. While there are no questions about a respondent's income and benefits or household consumption and expenditure, which would have allowed researchers to estimate the poverty level of female respondents, answers to questions on ownership of assets and access to resources in the general household questionnaire give some understanding of household economic welfare.

**48.** Tareque Md Ismail et al, 'Economic well-being and elder abuse in Rajshahi District of Bangladesh', *Research on Aging*, 37:2, 2015, pp.200-224

**49.** AKM NurunNabi, Abuse against older people within family setting among urban poor in Dhaka City, forthcoming

50. Bangladesh Bureau of Statistics, Violence Against Women Survey 2011, Dhaka, 2013, http://evaw-global-database.unwomen.org/-/ media/files/un%20women/vaw/vaw%20 survey/bangladesh%20vaw%20survey.pdf (23 December 2016)

**51.** The DHS Program: Demographic and Health Surveys website, www.dhsprogram. com (23 December 2016)

The DHS survey has a number of limitations. It is not possible to estimate violence and abuse of older women or women with disabilities and the module does not measure financial abuse or neglect.<sup>52</sup>

#### Pakistan

Two surveys, the Pakistan DHS and the Pakistan Social and Living Standards Measurement Survey (PSLM), regularly produce broad health and social statistics. The Pakistan DHS was conducted in 1990, 2006, and 2012, but only the most recent wave contains a module on domestic violence. In addition to this module, a section on 'husband's background and woman's work' includes a question on social attitudes regarding domestic violence and abuse. Female respondents aged 15-49 are asked whether a husband is justified in hitting his wife in certain situations (examples given are when the dinner has burnt or a child has been neglected). The module on domestic violence closely resembles the general DHS module on violence, focusing on emotional and physical abuse. It asks about lifetime experience of violence as well as the frequency of maltreatment experienced over the previous 12 months. It also examines the relationship between the respondent and the perpetrator. Questions regarding personal characteristics of respondents, intimate partners and members of the family, as well as risk factors such as female physical health, household economic welfare and living arrangements all appear on the questionnaire. The module collects data on whether an incident was reported and via what channels. In addition to the limitations of the general DHS domestic violence module, which is capped at age 49, and lacking questions on disability, neglect and financial abuse, the Pakistan DHS excludes questions on sexual violence. This is possibly due to cultural sensitivity surrounding the issue.

PSLM has been one of the main sources of data to monitor the Millennium Development Goals and is envisioned as a source for the SDG data. The survey collects data on education, health, employment, household assets, amenities, and satisfaction with services. The survey collects data on children under five and those aged 10 and over. The module on population welfare focuses on family planning. The topic of violence and abuse is not covered by the survey.

Pakistan is among 15 low- and middle-income countries out of 25 in the Asia-Pacific region that do not have a comprehensive ageing survey, and have not undertaken a dedicated survey on violence and abuse in later life.<sup>53</sup> Data on violence and abuse against older people is not collected by regularly administered surveys, either due to existing age caps or limitations of questionnaire design.

According to a WHO report in 2014, only 17 per cent of 133 countries had a national survey on elder abuse but nearly two-thirds of countries reported having a law against elder abuse.<sup>54</sup> This raises questions about how countries that do not have regular, comprehensive collection of data on violence and abuse in later life are able to develop evidence-based plans, policies and laws on this issue, or indeed targets and indicators enabling them to monitor progress.<sup>55</sup> For example, two provinces in Pakistan, Khyber Pakhtunkhwa and Sindh, have enacted laws for the protection of the rights of older people. These laws guarantee the provision of healthcare, shelter, income security and social protection. However, given the lack of sufficient and robust data in these areas, formulating policies aimed at implementing these laws will remain extremely challenging. Similarly, the Bangladesh National Action Plan to Prevent Violence Against Women and Children (2013-2025), in its overview of the current status of violence against women, does not acknowledge elder abuse and only reports prevalence of violence and abuse against women and children aged 15-49, without any age disaggregation.56

52. Recently, DHS has launched a disability module in six countries. https://dhsprogram. com/Who-We-Are/News-Room/Collaboration-yields-new-disability-questionnaire-module. cfm (23 December 2016)

53. Teerawichitchainan B and Knodel J, Data mapping on ageing in Asia and the Pacific: analytical report, Chiang Mai, HelpAge International, United Nations Population Fund (UNFPA), 2015, www.helpage.org/download/ 55c227b4c55d3 (23 December 2016)

54. WHO et al, Global status report on violence prevention 2014, Full report, Tables A4, A10, www.who.int/violence\_injury\_ prevention/violence/status\_report/2014 (23 December 2016)

55. Gelders B, Good practices and barriers in the use of data for policy and advocacy on ageing in Asia-Pacific, Chiang Mai, HelpAge International, 2015 http://ageingasia.org/ eaprdc0033/ (23 December 2016)

56. National Action Plan to Prevent Violence Against Women and Children 2013-2015 (2013), Ministry of Women and Children's Affairs, The Government of the People's Republic of Bangladesh

# Recommendations

The experience of preparing and publishing three editions of the Global AgeWatch Index has exposed significant gaps in internationally comparable data on ageing and older people. This report has shown that the journey towards fulfilling the objective of making high quality data indispensable to policy making for ageing societies will be long and arduous. A particular concern is that the complexities of old age are rarely adequately captured by data sets. Issues of health, income and personal security in older age are complicated by the impact of factors such as gender and ethnicity. The complex interactions of these dimensions of identity in old age cannot be reflected in single aggregate indicators. However, when disaggregated and analysed in greater depth, the data now being collected has the potential to shed new light on our understanding of ageing in different jurisdictions around the world, and the policies needed to support this growing sector of the population.

We conclude our analysis by making the following observations and recommendations:

# Using existing ageing-specific and general health and social welfare surveys, enhanced by redesign, can begin to close the evidence gap

There is a need to better exploit the data that is already available. For example, a data mapping study on ageing in Asia and the Pacific has shown that, out of 25 countries, 24 had censuses, 16 had DHS surveys and 10 had national ageing surveys.<sup>57</sup> These censuses and surveys contain socio-demographic data on older people, showing that data exists – but it requires time-consuming work to access, analyse and use the data to close knowledge gaps. Medium-term timeframes will be necessary, which funders need to be prepared to support.

Some relatively modest changes can be made to existing surveys that would significantly improve their value for understanding the dynamics of old age. For example, social protection modules should ask about receipt of transfers at individual level. Questions on why people do not work should not contain ageist language such as "too old" or "old age". Better analysis and more detailed reporting can support our understanding of ageing; to this end we believe that work dynamics should be reported by sub-age group (not just 60-plus, 65-plus) to show the diversity of employment circumstances. The key point here is that the experience of working is unlikely to be uniform in later life, however that is defined, with those aged 60-65 experiencing it quite differently from those aged 70-75, for example.

# Age caps should be removed from monitoring frameworks and survey collection

Issues arising from the use of age caps in health monitoring frameworks and surveys have been highlighted in this report. These age caps restrict both the development of policy and datasets to measure progress on implementation of policy, for example in relation to NCDs, HIV, and Universal Health Coverage as promised by the SDGs.

Notably, most DHS surveys are limited to the 15-49 age group. This represents an enormous missed opportunity; a loss of vital information about a growing and diverse sector of the population, just at a stage of life when significant and sometimes multiple health problems can arise. Surveys of older people can provide unique insights into old age, for example, by asking questions relating to inter-generational transfers. Currently two countries, South Africa and Haiti, have either removed or extended the age cap. WHO, likewise, should review current practice in relation to data collection on NCDs. The exclusive focus on people aged 30-70 in the mortality indicator guides programmatic responses neglecting older people and excluding a large proportion of those most at risk from NCDs.

57. Teerawichitchainan B and Knodel J, Data mapping on ageing in Asia and the Pacific: analytical report, Chiang Mai, HelpAge International, United Nations Population Fund (UNFPA), 2015, www.helpage.org/download/ 55c227b4c55d3 (23 December 2016) In addition to removal of all age caps, the violence and abuse module should be an integral part of the core DHS survey and should be administered in full without age caps. Currently, a stand-alone module is included as part of the standard DHS survey at the discretion of individual countries. Each country chooses which questions to ask, a feature which could lead to the exclusion of sensitive questions on sexual violence from the questionnaire.

# There is potential for innovative approaches in data collection

We believe that outpatient attendance records, which at clinic level are often of high quality, could be utilised for targeted interventions. Non-formal data sources such as participatory research studies, can also be used to verify official data. Additionally, older people themselves should be consulted during the process of survey development to help identify relevant aspects of ageing which should be measured.

# Make data openly available and ensure timely data is accessible to everyone

Data also needs to be released in a timely fashion to facilitate policymaking. Suzman (2010), for example, makes the point that 'cross-national research in both developing and developed countries has been seriously hampered by slow release of microdata, sometimes more than a decade after collection'. This was an issue for the current study in that micro-data from SAGE 2014 surveys in China and India remained unavailable to the end of 2016.

### Researchers and research centres need resources and support to develop the skills to collect and analyse data relating to key issues on ageing

In order to implement the SDG target of enhancing international assistance for capacity-building to support national plans for the SDGs, resources and support will be a critical requirement particularly in low- and middle-income countries. This may prove most feasible when combined with life-course approaches to data collection. National statistical offices, multilateral agencies, academia, civil society, and the private sector should work together to close the data gap, especially on issues where there is a paucity of data, such as that of violence and abuse.

## Conduct data mapping and develop statistical guidelines to inform action for improved data on ageing

Work on increasing gender-based data gathering has resulted in a number of valuable resources that will shape future research in this area. For example, the United Nations Department of Economic and Social Affairs Statistics Division (UNDESA) published guidelines on survey design, data collection, analysis, and reporting statistics on violence against women, and took stock of current knowledge on neglect, abuse and violence against older women.<sup>58, 59</sup> Data2X published an extensive report, *Mapping Gender Data Gaps*, summarising gaps in information on health, education, economic opportunities, political participation and human rights for 144 countries. In comparison, there are fewer resources for improving data on ageing.

The development of guidelines on the production of statistics on violence and abuse in later life can strengthen national surveys, encouraging countries to develop an evidence base on this extremely serious and hitherto under-reported issue. Surveys should include questions on prevalence of different types of violence and abuse (for example, physical, sexual, emotional, financial and verbal, or neglect), risk factors (for example, disability, poor physical health, mental health problems, poverty, social isolation, and living arrangements), frequency and duration of abuse; and channels through which victims seek help.

A recent mapping of ageing data focused on 25 Asia Pacific countries. However, there is a need to build an understanding of data availability, adequacy, coverage, regularity of production, comparability and gaps in other regions as well.

58. UNDESA Statistics Division, Guidelines for Producing Statistics on Violence against Women – Statistical Surveys, New York, United Nations, 2014

59. UNDESA Division for Social Policy and Development, *Neglect, abuse and violence against older women*, New York, United Nations, 2013, www.un.org/esa/socdev/ documents/ageing/neglect-abuse-violenceolder-women.pdf (23 December 2016)

### Governments and other agencies should be accountable for progress on the 2030 Sustainable Development Agenda

Data gathered under the aegis of the 2030 Sustainable Development Agenda should be accessible and openly available to the widest possible audience. For older people in particular, the "digital divide" may be especially challenging, and those generating, analysing and using data will need to ensure that it is available not only to policy makers, but also, in the most accessible form possible, to those who are most affected by its use: older adults in countries around the world.



# Conclusion

Many of the data gaps which we reveal in this paper are arguably rooted in a limited understanding of the variation in the ageing process and the range of experiences of older people, which often include a degree of continuity from earlier periods of life. The assumption that older people are uniformly in decline and in retreat from society diverts attention from their roles as carers, often of a spouse, their surprisingly high rates of labour force participation long past the age of 60, at least in some countries, particularly among men, their financial contributions to younger family members, it is not always the other way round, and the possibility that they, too, might have a sexually transmitted disease or be victims of abuse. Yet attitudes towards ageing that see it simply as a time of worsening health and withdrawal from social life have not prompted a sufficient focus on the kinds of data gathering and policy development that might ease some of the problems older people do indeed experience. Lifespans are lengthening, while employment is harder to find at older ages; chronic diseases are more likely to occur as we age, and the health, social care and income requirements of later life are real – if not uniform. Age caps of only 49 years, let alone 69, on data collection in vital areas such as health are striking in their short-sightedness, though resource constraints may also be a factor. We call on funders to take note of the importance of collecting the data that is missing on older age groups.

As we also observed in this paper, the lack of data does not necessarily prevent policies or laws being developed, but without an evidence base to understand the extent and nature of a problem, how can policy-makers succeed in solving it? And what is the cost of failure?

In order to meet the changing, and in some cases, urgent needs of older people, and to track the contributions they are making, we require fresh data alongside better use of existing data. Equally, the lessons yielded by this new information can help to reshape attitudes – and policies – towards this increasingly lengthy and varied period of life that all of us, if we are lucky, will one day experience.



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